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Youth with Disabilities Talk About Spirituality: A Qualitative Descriptive Study

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There is little known about what spirituality means for youth with disability or about the potential relevance of youths' spirituality in pediatric rehabilitation. This study explored perceptions of spirituality for youth with disabilities. Using a qualitative descriptive methodology, we examined the lived experiences of eighteen youth ages 11-20 years with disabilities including cerebral palsy, central nervous system disorder or autism spectrum disorder. In individual interviews, followed by a focus group, youth identified key spiritual themes – the importance of their beliefs, personal sources of comfort and strength, finding purpose in helping others, significance of personal connections, and strengths-based perspectives on disability. This study makes a unique contribution by informing health care professionals about the relevance of youths' spirituality in service delivery. Keywords: Spirituality, Religion, Disability, Youth, Adolescent, Quality of Life, Qualitative Descriptive.

A primary feature of adolescence is the growing sense of self in the world through the development of knowledge, skills, and attitudes preparatory for adulthood. This is typically achieved by learning through formal education, exploring interests and developing skills and abilities within recreation and leisure, volunteer and work activities, as well as taking on various roles with increasing independence and responsibility. As part of developing their personal identity, youth often exhibit a stronger movement toward developing relationships outside of family, along with an emerging sense of empowerment in taking on adult roles and formulating a sense of direction for their life. Youth's spirituality is thought to be significant in the development of a healthy, positive self-identity that is foundational to the moral and civic responsibilities of adulthood (Lerner, Alberts, Anderson, & Dowling, 2006). Spirituality in children and youth has been identified as a source of motivation that has been largely unrecognized within developmental frameworks (Hart, 2006). As Hart (2006) posits "Children already have a spiritual life; they have access to wisdom and wonder, struggle with questions of meaning and morality, and have a deep sense of compassion" (p. 175). Accordingly, their spirituality cannot be ignored.

As a construct, spirituality is difficult to understand due to a wide variety of definitions as well as the diversity of ways in which it may be investigated (Larimore, Parker, & Crowther, 2002; King, M. et al., 2006; Shek, 2012). However, it is primarily viewed as having a positive influence and is increasingly recognized as relevant for youth in relation to

their global QOL or life satisfaction (Kelley & Miller, 2007), well-being and happiness (Holder, Coleman, & Wallace, 2008). The spiritual attributes of youth, including their sense of existential well-being (purpose, meaning, sense of future), was found to be relevant to their overall quality of life (QOL) (Sawatzky, Gadermann, & Pesut, 2009). In particular, “feeling good about the future” and “peace of mind” were important to the youths’ physical and mental health status. In adolescent mental health studies, a relationship between spirituality, health and QOL has been identified (Ferriss, 2002). A systematic review of recent research in adolescent religiosity/spirituality and mental health indicates that in 90% of the studies reviewed, adolescents who reported higher levels of religiosity/spirituality were also more likely to report having better mental health (Wong, Rew, & Slaikey, 2006).

Study of the spirituality of sick children who are hospitalized has been emerging in recent years (Feudtner, Haney, & Dimmers, 2003). However, within the field of pediatric rehabilitation, research related to spirituality has tended to focus more on the families of children and youth with disabilities (King, G.A. et al., 2006; King, G.A., Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009) or on adults who are reflecting retrospectively about spirituality in the context of their childhood disability experience (Schulz, 2005; Specht, King, Willoughby, Brown, & Smith, 2005).

The perspectives of youth with disabilities need to be considered (Rosenbaum, Livingston, Palisano, Galuppi, & Russell, 2007) as youth have an “inner life” (Boston, Mount, Orenstein, & Freedman, 2001) that can contribute to our understanding of their QOL (Davis et al., 2008). Optimizing QOL can be considered a key goal in pediatric rehabilitation (King, G.A. et al., 2002). In a quantitative study of QOL for youth with physical, developmental or communication conditions, McDougall, Wright, Dewit, & Miller (2014) identified a positive correlation between spirituality (defined as “any strong beliefs or feelings the youth may have”) and QOL. In past qualitative studies that have explored what youth with disabilities think is important to their QOL, youth rarely self-identify “spirituality” as significant. However, factors/themes have been identified that youth may not immediately recognize as being reflective of this concept, such as life fulfillment, personal growth, intrinsic strengths, relationships, and coping (Berntsson, Berg, Brydolf, & Hellstrom, 2007; Ronan, Rosenbaum, Law, & Streiner, 1999; Shikako-Thomas et al., 2009; Squitieri, Larson, Chang, Yang, & Chung, 2013). Even though youth perceptions are considered valid and valuable (Shipman, Sheldrick, & Perrin, 2011; Singh & Ghai, 2009; Stevens, 2010), and may be different from their parents (Shipman et al., 2011), there are few studies available that specifically examine how youth with disabilities conceptualize spirituality or their perceptions of the relationship between spirituality and their QOL.

The current paper is part of a larger qualitative study where the overall purpose was to learn what youth with disabilities find meaningful and important to their QOL. The concepts of self-determination and spirituality were focused on specifically in this study because little is known about whether and how these concepts are important to the QOL of youth with disabilities. The factors youth think are important to QOL and the link with self-determination were described in a separate paper (see McDougall, Baldwin et al., 2015). Indeed, in that paper, purpose was found to be integral to youths’ definitions of QOL, and personal growth and self-understanding were identified as important to youth’s overall sense of QOL (McDougall, Baldwin et al., 2015). The objectives that are addressed in this paper include: (a) specifically exploring what “spirituality” means to youth with disabilities; (b) understanding what they do to keep their sense of spirituality strong; (c) understanding if and how they link spirituality with their QOL; and (d) discovering if their spiritual beliefs are the same or different from their family. Through qualitative study into the meaning of spirituality for youth with disabilities, we can support the development of definitions and measures for this construct that more accurately reflects how youth perceive spirituality and how

spirituality may contribute towards their QOL. The meaning and importance that spirituality can have for youth with disabilities may carry important considerations for pediatric rehabilitation practice.

Role of the Researcher

The research team consisted of six people who collaborated on all aspects of the study and included two clinician-researchers (P. Baldwin and J. Evans) who interviewed the participants, two research study project coordinators (N. Etherington and M. Nichols), and the research study investigators (V. Wright and J. McDougall). These individuals have various backgrounds, including education, psychology, sociology, physiotherapy, occupational therapy, theology, coaching, working with youth, and qualitative research design. Specifically, P. Baldwin is an occupational therapist and clinical practice coach who works at a children's rehabilitation centre in London, Ontario. She has a Masters of Theological Studies, having completed an independent study of the spirituality of persons with disability. J. Evans was a physiotherapist at a children's rehabilitation centre in London, Ontario at the time of this study, and has since then attained a Master of Arts in Spiritual Formation. She currently works in private practice as a Spiritual Director. Both clinicians each have over thirty years of experience in working with children and youth with disabilities, including extensive strengths-based interviewing experience. N. Etherington is a PhD Candidate in Sociology at Western University whose research focuses on health over the life course. M. Nichols has a Master of Science in Human Development and Family Relations, with interests in child and adolescent development and parent/child relationships. V. Wright is a pediatric physical therapist and Senior Scientist at a children's rehabilitation centre in Toronto, Ontario. Her primary interests relate to outcome measurement creation and validation and clinical trials in pediatric rehabilitation. J. McDougall works as a researcher at a children's rehabilitation centre in London, Ontario. She has a PhD in Rehabilitation Sciences. Her primary research interest is examining changes in QOL for children and youth with chronic conditions and disabilities, along with related factors.

Methodology

Ethics approval for this research was received from the Health Sciences Research Ethics Board, Western University, London, Ontario, Canada. The study used a qualitative descriptive methodology (Sandelowski, 2000) that falls within a phenomenological approach in order to understand the "lived experiences" of the individuals of interest (Creswell, 1998). This was accomplished through listening to individuals' own perceptions as phenomenology considers only those who have lived the reality being studied a legitimate source of data (Baker, Wuest, & Stern, 1992). Following this design, participants were asked meaning questions to ascertain their experiences, from which a description of their accounts emerged (Morse & Field, 1995).

Researchers "stayed close to the data" (Sandelowski, 2000) in the coding and analysis of youths' responses.

Participants and Recruitment

Youth for this study were recruited from a children's rehabilitation centre in Ontario, Canada. Youth with disabilities between the ages of 11 and 20 years who lived within a 100 kilometer radius of the centre and were considered to have the cognitive ability to respond to open-ended questions in an interview format were eligible for the study. Exceptions for

recruitment included youth with progressive conditions where life expectancy could be substantially diminished and any youth who were already participating in the quantitative arm of a longitudinal QOL study (see McDougall, Wright et al., 2014) occurring during that same time period.

Potential participants were nominated by clinicians at the children's rehabilitation centre, who reviewed their caseloads to consider youth they felt would be interested in participating and who met the inclusion criteria. These youth and families were sent an information package from the centre's Quality Management Director. Potential participants had the option to accept or decline to participate by completing a form indicating their choice. Those who did not return a form were called by a study project coordinator. For youth who agreed to participate, an interview date was set up.

Date Collection and Analysis

The research team designed a semi-structured interview schedule as well as a focus group. The interview schedule began with a series of factual and warm-up questions (e.g., age, grade, who lives in home, leisure interests) to build rapport and to develop participant's comfort in being interviewed and audiotaped. Open-ended questions to provide participants with the opportunity to respond freely using their own words and concepts were developed to inquire about youth's understanding of the concept of spirituality and its relationship to QOL. The key questions related to spirituality included: (a) When you think about the idea of spirituality, what does that mean to you; (b) What things do you do that keep your (use participant's words for spirituality) strong; (c) Do you think there is a connection between this (use participant's words for spirituality) and your QOL; and (d) Would you say your spirituality is the same or different from other people in your family? After seeing a pattern in the first few interviews of youth wanting to share a "message," the research team added a question in the interview pertaining specifically to what the youth wished others to know.

Prior to the interview process, the two clinician-researchers provided the research team with a summary of their worldview in order to clarify and to support a stance for open listening to participants' perspectives. Participants were randomly assigned to an interviewer to complete one face-to-face interview per participant. Interviews were about 90 minutes in duration. The study information letter was reviewed with the participant and one of their parents. Written consent was obtained from both the participant and parent. Seventeen of the interviews occurred in a private area in the participant's home. One interview occurred in a private area of the rehabilitation centre at the participant's request. One of the participants requested that his parent attend the interview to assist with communication.

The interviewers used a slow, facilitative approach to provide participants with time and freedom to reflect upon the questions. Verbal and non-verbal forms of acknowledgement and affirmation of participants' responses and strengths were used. Clarification of participant responses was sought through summarizing as well as reframing or repeating questions where appropriate. Questions such as "what else?" and "can you give an example of when that happened?" were offered to support participants in expanding upon their responses. Visual cue cards and sticky notes to highlight key words were also used as needed to support participants' responses to questions. Interviewers were attentive to verbal and non-verbal cues to determine when participants had finished exploring a question or whether further probing was appropriate. Upon completion, interviewers recorded summary notes and observations, also noting any technical, procedural, environmental, or participant-related issues that may have affected the quality of the interviews.

Participant interviews continued until it was determined by the research team that a point of informational saturation had been reached (Guest, Bunce, & Johnson, 2006). All

interviews were audio-recorded with the participants' and parents' consent and were later transcribed verbatim. Digital recordings were uploaded to an encrypted website by the project coordinator and accessed by a professional transcriptionist. Any identifying information was removed from both summary notes and the transcript to protect the identity of the participants. Interviewers reviewed the completed transcriptions to verify accuracy and the project coordinator then imported them into NVivo10. Interviewers and the project coordinator (PB, JE, MN) independently coded each transcript for high-level themes. The project coordinator (MN) then completed line-by-line coding of the transcripts, and generated a codebook that contained all codes. The codebook was checked for accuracy and comprehensiveness against each interview by one of the study investigators (JM). A second project coordinator (NE) completed a line-by-line coding of excerpts from three randomly selected interviews and coder agreement was reached at 86%. Where there was disagreement, it was because the second coder had not assigned a code to a line. After discussion, the second coder agreed that the code assigned by the first coder was suitable. Over several research team meetings, codes were collapsed and "meaning units" or groupings of statements were derived from the data. Finally, overarching factors and themes from clusters of meaning units were determined by the research team.

Triangulation of the data (Krefting, 1991) occurred through comparing the overarching ideas and concepts identified by interviewers within each interview to the factors and themes which emerged from collapsing codes and examining in-depth meaning. In addition, member checking, or respondent validation (Krefting, 1991) was completed in two ways. First, summaries of the study findings were mailed to participants, who verified accuracy of the findings and provided additional information if they felt it necessary. Second, a focus group comprised of study participants enabled further consideration of and reflection on the findings. The initial categories and thematic analysis from the individual interview data was used to develop the focus group questions. Feedback from both the focus group and the mailed-in responses was used by the study team to refine the study results.

Results

Participants

Eighteen participants between the ages of 11 and 20 years participated in the study. Fifteen were attending school at the time of the interviews, two had finished high school and one was attending college. All were living at home at the time of the study. Table 1 provides further demographic data.

Table 1. Demographics

Gender	Age	Grade	Chronic Condition
Male	17	12	Cerebral palsy
Female	15	10	Other
Female	16	12	Cerebral palsy
Male	19	12	Other central nervous system disorder
Male	17	12	Other central nervous system disorder
Female	19	Post-secondary	Cerebral palsy
Female	11	6	Cerebral palsy
Female	20	12	Cerebral palsy
Female	12	7	Cerebral palsy
Male	19	12	Cerebral palsy

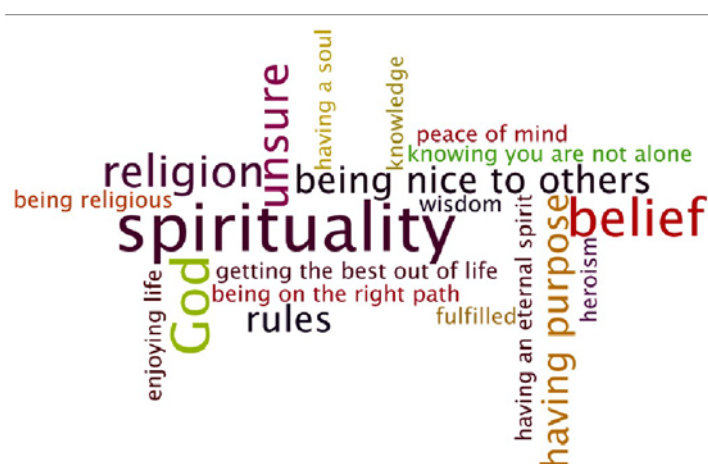
Male	20	Not in school	Asperger's Syndrome
Female	20	12	Cerebral palsy
Male	19	12	Asperger's Syndrome
Male	19	12	Asperger's Syndrome
Male	19	Not in school	Developmental delay
Male	19	12	Cerebral palsy
Female	13	8	Cerebral palsy
Male	18	12	Autism

All participants responded to questions about their spirituality and most were comfortable in discussing their spirituality in detail. In comparing the responses from youth ages 11 to 16 years with youth ages 17 to 20 years, there were no appreciable differences in their definitions; however, older youth were generally able to provide greater detail in their responses. There were also no appreciable differences in how youth responded to the questions about spirituality related to diagnosis or place of residence (rural or urban).

Youth Definitions of Spirituality

In response to the question asking the youth what spirituality means to them, sixteen participants provided an immediate response. Of these, eleven identified spirituality within a religious context, naming a relationship with God or a higher power. One participant responded that God does not exist, basing this upon shared beliefs with Steven Hawking, whom he saw as a mentor because of having a disability. Another reported that spirituality did not mean anything to her, adding that she did not believe in God. Three participants identified spirituality in existential or philosophical terms such as “having a life that’s unique” or “everything happens for a reason.” The third identified spirituality as having a purpose in life. Of those who provided an immediate response to what spirituality means to them, one participant identified spirituality as being satisfied with making a contribution. Figure 2 depicts a Wordle of the phrases used by the youth to describe their spirituality. The size of font reflects the frequency of youth’s responses.

Figure 1. Youth Definitions of Spirituality



Key Spiritual Themes

Through analysis of the youths’ perspectives of spirituality, including their responses

to common descriptions of spirituality and what things keep their spirituality strong, five inter-related spiritual themes were identified: the importance of beliefs, sources of strength and comfort, finding purpose in helping others, personal connections, and perspectives on disability. Participant quotations selected to reflect the range of youth's perspectives related to these themes can be found in Table 2.

Table 2. Spiritual Themes and Participant Quotations

Theme	Sample Quotations
Importance of Beliefs	<p><i>"Well, I think it's something inside yourself that helps you get through...you can turn to whatever you feel, or whatever you believe is out there...I personally believe in something bigger than myself, I'd like to believe it's God, but...I also strongly support other religions as well."</i></p> <p><i>"You have to believe in yourself to have your dreams and goals."</i></p> <p><i>"Well...believe in God, definitely...there's someone like, watching over you...and it helps you."</i> <i>"[Having a soul] is caring about stuff, a soul is what makes you laugh."</i></p> <p><i>"The Lord...he's the one who created everything...He made me to...be what I ...who I am."</i></p>
Sources of Strength & Comfort	<p><i>"I know God's there for me whenever I need it."</i></p> <p><i>"If you surround yourself with positive and uplifting things or uplifting people that can remind you about life and its purpose, then it's better for you."</i></p> <p><i>"When I know I'm doing wrong, a stabbing pain is in my heart and that means I know I did something totally wrong...when that happens, I stop right away...I turn around and go for the better."</i></p> <p><i>"Knowing there's a Higher Purpose looking out for me means I don't have to rely on friends or family members or teachers to keep me safe."</i></p> <p><i>"[Praying] makes me go to sleep knowing that I'm doing the right things."</i></p> <p><i>"Sometimes that belief [in self] changes, that belief can kinda get lost sometimes...but when I get that moment of clarity, I'm like ok, I can do this...and I know I can get through it."</i></p>
Finding Purpose in Helping Others	<p><i>"...everybody wants a purpose...I need to do another analogy...there's a colony of mice and, ... each mice wants to have a job, a purpose, like, one can find the cheese, and one could scare away cats, one could be a teacher, like...everybody wants something to do in life and a reason to exist."</i></p> <p><i>"Helping others just makes me feel like I have a purpose for getting up in the morning because I can help someone. Or maybe I can help someone laugh today or get a different perspective on mental illness, or that sort of thing."</i></p> <p><i>"I don't think it's enough to just be happy as a person until you've done something for someone else. I couldn't be happy without knowing that I've made others happy as well."</i></p> <p><i>"I guess I feel better about myself when I help someone. When I'm helping others I feel closer to God."</i> <i>"I might want to leave something good for other people...[something] useful, before I die"</i></p> <p><i>"Each day I pick one person that I want to like, keep going for, and that's enough for me each day."</i></p> <p><i>"Helping people that are less fortunate than me, and giving them a voice really helps me realize that it's important that everybody's important."</i></p> <p><i>"When I'm really struggling, it just helps me think, okay, maybe I will get something out of this, like, maybe I'm supposed to go through this so that I can help someone else later in life who might be struggling in the same issue."</i></p>
Personal Connections	<p><i>"If you're aware of yourself then, and you're happy with yourself, then you can be happy with the choices you make. And that'll lead to a better quality of life."</i></p> <p><i>"My friends and family have had a great influence on my life...the lessons they've taught me...and the way they've improved my way of living."</i></p> <p><i>"I don't know, just to me, I feel connected, like, with other students and staff and teachers and parents who are, like, going through the same things."</i></p> <p><i>"I've learned to always have good close friends that I can trust because it's always important to have someone...who you can go to in a time of need...and something bigger than me...it's taught me to appreciate who I worship."</i></p> <p><i>"Connecting with [pets]...because they don't talk they just kind of sit there and they love you unconditionally...they teach you that it's okay to receive love, it's okay to receive things unconditionally as well"</i></p>

Perspectives on Disability *"Don't give up...have faith in yourself and...don't let other people say you can't do this...you can do anything you put your mind to."*
"If you believe you can do it, then you can do it." *"It's ok to be different."*
"I'm so used to having the disability that it doesn't even matter...what I can't do. Having a disability drives you more than another person...disability makes your sense of purpose strong."
"The important thing is that I hope everybody well in my life because I don't want to see them go in an ambulance...I've been in one, an ambulance."

Life Mottoes:

"Just live today because anything could change, like, your idea of what you want to do, everything could change, like, any day, so as long as you keep going one day at a time, then everything will eventually pan out."
"Help people when you can and then...do good things to other people." *"All things happen for a purpose."*
"Live each day as best [you] can."
"If people are down on themselves and they say I don't want to be in this world, they should [remember]...God gave them a good earth to live on."
"Words are meaningless without action."

The importance of beliefs. Participants spoke of a belief in God, a belief in a power within themselves, and a belief in self. Beliefs were thought to be personal, and a diversity of beliefs were recognized and valued.

A belief in God was most often described within a Christian or "religious" context, with some participants describing God as "bigger" or "higher." Although God was often described as "out there," many participants also spoke of an inner sense of connection with God. One youth described his belief in God within a context of heroism and wisdom. Two of the youth who spoke about their Christian beliefs also described the positive influence that beliefs such as Buddhism had on them in expanding their perspectives.

A belief in a power within themselves was shared by several youth. One spoke about a belief in an inner self that provided a source of strength and clarity, while another participant spoke about having a soul that causes you to care and to laugh, and having "a heart that helps you to love."

Having a belief in oneself was described by one youth as a foundation for having dreams and goals while another participant linked faith in self with a sense of perseverance. A third talked about reliance on oneself for dealing with tricky situations. Another youth described his belief in himself as a "good guy" because of attributes such as honesty and love.

Sources of strength and comfort. Participants' various beliefs were described as important, providing guidance to the youth for living as well as a sense of determination. Beliefs were also related to having good relationships with others, knowing oneself, being true to oneself, and feeling good about oneself in terms of personal strengths, abilities, and purpose in life. Seeing themselves as having character strengths such as compassion, intelligence, confidence, and a sense of humour as well as having various interests, skills and abilities was important to all of the youth. Several described their inner beliefs as a positive support for learning what to expect from life and developing peace of mind. When asked what helped them to stay strong in their spirituality, participants identified individual practices such as positive self-talk, meditation, listening to or playing music, following routines, and creative self-expression through art and writing. Some spoke of the need for time alone while others identified the importance of interacting with others.

Of the participants who reported religious beliefs, several identified a sense of comfort that resulted from this belief. Two individuals reported having a sense of comfort and hope based on their belief in an afterlife. Another youth talked of the happiness that results from his belief in God creating him to be who he is. Several of the youth who identified their

beliefs within a religious context identified prayer as a personal practice, describing it variously as a source of comfort, a way of making requests to God, a way of giving thanks, and a way of having hope.

One youth talked of how prayer is available to her at any time.

Finding purpose in helping others. In discussing their spirituality, several youth identified having a sense of purpose in life as important, providing direction for decisions in daily life, and related to making a difference in the world. Many of the youth talked of expressing their spirituality through helping others. This outward focus was described in various ways such as being kind to others, making life better for others, being open and accepting of others, listening, respecting differences, providing words of encouragement, and caring for the environment. Small acts of kindness were recognized as significant: smiling at someone, making cards for people when they are sick, making someone laugh, calling people on the phone to encourage them, lending a hand or a small amount of money. Some spoke of helping through prayers or “well-wishes” for others.

Participants expressed a variety of reasons for helping others, including having a sense of well-being, sense of confidence, feeling closer to God, and living the “golden rule” of treating others how one would want to be treated. Several participants specifically discussed the mutual benefits in helping others, such as shared feelings of love and belonging, learning that occurs through the interactions, and giving and receiving encouragement as a way of keeping strong spiritually. Several youth indicated their spirituality was strengthened through their ability to have a positive impact on others. They spoke of a sense of personal happiness as well as the sense of increased determination that results from the satisfaction of helping others.

Personal connections. In talking about their spirituality, all youth discussed the importance of relationships in providing a sense of connection. Being connected with self, others (family, friends, pets, professionals/care-givers), and God were referenced. The quality of these connections was considered important in expanding youths’ perspectives and learning as well as providing a social support system of acceptance, encouragement, participation, and practical help.

Several youth identified the relationship with self in terms of the self-awareness and self-knowledge that they associated with meaningful participation, making choices, and being in positive relationships with others. Having an inner awareness of doing wrong, or of having “sinned” was described as helpful by a few of the youth as it caused them to turn towards God in prayer or to take corrective actions. One participant spoke of being able to apologize to others as an important element for restoring positive relations with others.

Overall, participants expressed a deep appreciation for their family and friends’ love, emotional support, encouragement, guidance, and practical support. Pets were identified by many youth as being integral to the family, providing companionship and friendship.

Professional relationships (teachers, therapists, assistants) were described as helpful in providing emotional support, challenge, guidance, encouragement and accommodations for their disability. Respectful dialogue about beliefs was identified by some participants as a way of making sense of life experiences, especially in conversations with peers and with adults such as parents and teachers.

The relationship with God was described as important to some in terms of comfort, reliance, and guidance. For those who identified their beliefs within a religious framework, spiritual practices that connected them with God included formal worship services, membership in youth group, private prayer, meditation, art, and music. For youth who attended church, their participation was variously described as an opportunity to learn more about God, participate in worship, contribute to their spiritual community, and receive guidance for living.

Perspectives on disability. Within the context of exploring their perceptions of spirituality, some of the youth spoke of the realities of limitations caused by disabilities at the same time as describing advantages and necessary attitudes for living with disability. Several youth identified the learning that came from their experience as a way of taking a positive perspective on their situation. One spoke of how using a wheelchair isolated her from some peers, while at the same time, it allowed her to participate in activities with other peers who were also wheelchair users. Another youth reframed his inability to read by focusing on the strengths of his intelligence and excellent memory.

Several shared how their spirituality supported them in the challenges of life, describing how their disability experience led to a strong attitude of determination, a desire to connect with and help others, and a practical sense of resourcefulness for coping. One youth described how his disability caused him to be even more determined to find fulfillment in life through helping others, while another spoke about the hope that her struggles would prepare her to be able to help someone else later in life. They offered messages of encouragement for other youth with disabilities through their use of “life mottoes” that reflected the learning gained from their experiences, a few of which are highlighted in Table 2.

Connecting Spirituality with Quality of Life

When asked whether their spirituality was linked with their QOL, sixteen youth expressly affirmed a positive relationship between the two, one participant did not link them at all, and one was not asked as the abstract concepts were too difficult. The element of receiving guidance or a sense of direction that came from spiritual beliefs was identified. One youth reported that “being on the right path” was related to a higher QOL and that being lost or confused resulted in a lower QOL. Many spoke of the “goodness” of life and seeking a good life, which came from caring for and helping others. Several identified the help and strength received through their sense of spirituality that supported their feeling of happiness.

Youth, their Families, and Spirituality

Youth were asked if their spirituality was the same or different than that of their family. Of the eighteen participants, twelve identified their spirituality as similar to some members of their families, while the remainder either identified their spirituality as different from family, not discussed with family, or they did not respond to the question.

For youth who saw their spirituality as similar to their family, most attended church with their family and had shared perspectives on how to treat others. A few of these participants explained that their family supported them to make personal choices about whether or not they attended church. One youth described how similar denominational beliefs within the family did not necessarily mean that they agreed on everything.

Of those who identified their spirituality as different from their family, one youth described her sense of spirituality as emanating from within herself while her family would see it as linked with external sources. Another youth stated that his disability meant that he “sees things differently” in terms of his spirituality as compared to his family. A third talked about how the differences in spirituality within the family (Christian and Pagan) resulted in her having a greater sense of respect and openness towards the diversity of beliefs in others.

Discussion

Based on limited existing literature on how youth with disabilities may perceive spirituality or the potential role that spirituality plays in their life, our objectives were to

explore in-depth what spirituality means to youth with disabilities and what they do to keep their sense of spirituality strong. We also aimed to understand if and how youth link spirituality with their QOL, and to find out if youths' spiritual beliefs were the same or different from their family's beliefs. The findings from this study suggest that spirituality is indeed important for many youth with disabilities, and that it is personally understood and deeply meaningful, influencing youths' decisions, relationships, and QOL. Their spirituality may or may not be experienced within a religious framework and can be the same or different from their family's beliefs.

There seemed to be a greater proportion of youth with disabilities in this study who defined their spirituality within a religious context as compared to Canadian youth overall. In surveys of 3500 Canadian youth ages 15-19 years between 1984 and 2000, Bibby (2001) found that youths' spirituality was most often expressed in the form of existential "why" questions. In contrast, the youth in this study tended toward more "how" questions, focusing on ways of living well within their present lived context. The diverse definitions of spirituality that were shared by participants indicate that we are well-advised to inquire of the youth themselves what spirituality means to them and what/if any role it plays in their life.

In adults with disabilities, spirituality has been identified as a support for coping and resilience (Gall et al., 2005; Specht et al., 2005). In children with chronic illness involving hospitalization, the role of religiosity/spiritual coping strategies was also identified as important; however, children's spiritual coping strategies were unique from adult coping strategies (Pendleton, Cavalli, Pargament, & Nasr, 2002). Participants in this study affirmed the positive role of spirituality in their lives. They perceived their spirituality as an integral part of their life, with their beliefs and practices providing a positive source of strength and comfort. This suggests spirituality may play an important role in supporting the resilience and coping of youth with disabilities and would benefit from further study. Whether expressed as religious practices such as prayer or church attendance, or as activities that others may view as non-spiritual such as taking a walk, painting, or listening to music, it is important to recognize that any activity may have an important spiritual meaning for youth. In thinking about activities of therapeutic value for youth with disabilities, therapists need to consider and explore the potentially deeper levels of meaning attached to the tasks themselves, as this may be a source of motivation not previously considered (Hart, 2006; King, G.A., 2004). As well, developing accessible methods for youth-selected spiritual practices at home or in their community could become an important therapy goal. Therapists may need to consider linking youth with community-based spiritual resources of the youth's choice, or providing disability education within spiritual communities in order to support inclusion (Speraw, 2006).

Spirituality can play a significant role in the positive development of self-identity, supporting youth to become productive adult members of their community (Lerner et al., 2006). Overall features of spirituality expressed by participants included both personal and transpersonal elements. A strong relational spirituality (Hart, 2006) was evident in participants' sense of interconnectedness, deep respect for a diversity of beliefs, and their expressions of appreciation and compassion for others. They value their relationships and create meaning out of their lived experiences by learning from their interactions and by seeking to help others. These youth demonstrated a spiritual maturity (Fowler & Dell, 2006) and wisdom (Hart, 2006) in their understanding of relationships as being mutual, recognizing the importance of both giving and receiving; being interdependent, as valued over independent; being inclusive, focused on the commonalities between self and others; and being complex, noting the richness of learning and of teaching that extend from their interactions with others, including family, friends, service providers, God, and even strangers who were important in their relational web.

Compassion for others was strongly emphasized by the study youth as they spoke of their desire to offer assistance, wisdom, encouragement, and comfort to others who are going through difficult challenges. These youth appeared to seek out opportunities for altruism and expressed how these provided them with a sense of purpose, leading to an enhanced QOL. Altruism has been defined as an “other-regard” (Post, 2005), of being invested in the interest of others with whom one has interrelations (Morrison & Severino, 2007), and has been associated with QOL (Post, 2005). It is important to note that the apparent motivation for altruism, as identified by these youth, is not self-oriented in terms of gaining life skills or opportunities and connections for their future; rather, the youths’ comments indicated that it is self-giving and seems to come from a sense of gratitude for the goodness and kindness they have received from others.

Recognizing this reciprocity in relationships needs to be included as an indicator of child/youth well-being (Foley et al., 2012) and it is also important for service providers to consider how they might work to validate and facilitate opportunities for expressions of altruism for youth with disabilities. These opportunities must match the individual’s style and interest and may be reflected in a variety of ways, such as small acts of kindness offered to friends, neighbors or peers, relational supports to others, or formal volunteering opportunities.

The majority of youth in this study clearly affirmed that spirituality is related to their QOL. Similar to adults reflecting on their experience of childhood onset disability (Schulz, 2005), these youth were deeply reflective of their life experiences, perceiving a sense of purpose as an important element of QOL. A spiritual worldview can provide “an ultimate vision of what people should be striving for in their lives” (Pargament & Park, 1995, p. 15) and having goals can provide an important source of meaning thought to produce well-being (Emmons, 2005).

Spirituality may serve as underpinning in terms of making sense of life experiences, including disability. In exploring their spirituality, the youth in this study expressed how their spiritual beliefs can offer a lens through which they can develop a larger sense of meaning related to their disability experience, as seen in their advice or “life mottoes,” and a sense of purpose in life related to helping others that may enhance their hopes for the future. This may ultimately serve to strengthen their determination, resourcefulness, and goal attainment in many practical ways.

The capacity of many youth to frame their disability in terms of opportunity was remarkable, and their self-understanding seemed connected to their acceptance of disability (Berntsson et al., 2007). First, it was uncommon for them to refer to their disability or related issues in negative ways when discussing their QOL: a finding similar to that noted by other researchers (Shikako-Thomas et al., 2009). Secondly, when youth did reference disability or when this was specifically asked about during the focus group, they reflected on the gifts and opportunities that arose in the context of their challenges. They highly valued learning from their life experiences, whether it was in terms of developing personal resourcefulness, recognizing benefits of having a disability, valuing the interdependent nature of relationships, or recognizing ways they could make a positive contribution in their world. Thus it appears that to improve QOL, it is not only important to attend to enhanced social participation, but also to attend to the underlying beliefs and personal meaning (King, G.A., 2004) that may motivate youths’ participation. This tailored support can aid youth in exploring the link between their aspiring virtues and the positive contributions they can make in their world. Since youth with disabilities may assume a positive stance toward their disability, they may best be supported by a positive orientation or strengths-based practice by therapists. Within a strengths-based orientation (Park & Peterson, 2009), therapists can seek to discover and enhance the strengths of clients as well as considering how the strengths of their families can

act as a resource.

The affirmation of a strong link between spirituality and QOL by these youth and their comfort in talking about their spirituality suggests that those who are interested in enhancing the QOL of youth with disabilities need to recognize the holistic nature of youth's QOL. Taking spirituality into account can be considered an integral component of holistic health care services (Hodge & Horvath, 2011) and developing measures that reflect the impact of spirituality can be an important aspect of health and social services (King, M. et al., 2006). While the findings of this study cannot be generalized to all youth with disabilities, it certainly appears that a sensitive and respectful inquiry about youths' spirituality as a part of holistic pediatric rehabilitation would be worthwhile. Although recognized as relevant to health care and supported by spiritual care disciplines within hospital settings, spirituality is not typically addressed within the context of community-based pediatric rehabilitation, nor are spiritual care supports provided within the typical array of services within this geographic region (Baldwin, McDougall, & Evans, 2008).

With the majority of youth in this study identifying spirituality as relevant to them related to their QOL, it will be important for organizations to consider the adoption of a holistic approach to services and the creation of opportunities and training for therapists to increase their awareness and response to how youths' spirituality may intersect with goals for therapy. While therapists may be reticent and unprepared to engage the topic of spirituality with their clients (Egan & Swedersky, 2003; Engquist, Short-DeGraff, Gliner, Oltjenbruns, 1997; Johnstone, Glass, & Oliver, 2007; Morrison-Orton, 2005; Wrigley & LaGory, 1994), the youth in this study were comfortable, open, and deeply reflective in their discussions when specifically asked about their spirituality. Although youth described the positive attributes of their spirituality, there may be some who desire more specialized spiritual care supports, especially if they are struggling with the impact of disability or if spiritual beliefs are constraining. Organizations may wish to consider the development of collaborative partnerships with spiritual care services for these circumstances.

In this study, youth generally reported a positive relationship with their family, describing their family's spirituality as a resource to them in exploring their own spirituality, regardless of whether there was agreement on beliefs or not; therefore taking a family-centred approach to spirituality may be beneficial. In addition, families may desire that therapists acknowledge the role that spirituality plays in their lives (Speraw, 2006). General guidelines for integrating spiritual inquiry into health care practice are emerging (Barnes, Plotnikoff, Fox, & Pendleton, 2000) and youth responses to the open-ended, strengths-based questions used in this study indicate the value of inquiry using these types of questions. Table 3 provides additional tips for therapists' consideration based upon the responses of youth in this study.

Table 3. Tips for Therapists

1. Use strengths-based open-ended questions to explore spirituality such as: What are your hopes?
What helps you stay strong?
Do you have spiritual beliefs or practices that are helpful for you? If so, how are they helpful?
What are you learning from your unique challenges? What's important about that? Is there a way you might like to share what you're learning with others?
2. Support opportunities for altruistic endeavors – caring for and helping others
3. Identify and compliment youth on their character strengths
4. Explore what helps youth to stay strong, including spiritual practices
5. Ask youth how they see themselves contributing to making the world a better place
6. Support opportunities for youth to share the wisdom they have learned from their lived experience – youth mentoring youth, youth sharing their stories through writing or speaking

As this was a small study that reflected primarily Christian beliefs, a larger study of spirituality in youth with disabilities that encompasses a wider range of beliefs is recommended. Further study of the spirituality of youth who have acquired disability during their adolescence as well as youth with progressive disorders should be considered as an important next step in understanding the role of spirituality within pediatric rehabilitation. While youth were comfortable and able to discuss their spirituality, their spirituality was initially alluded to in terms of fulfillment and purpose in their early discussions of what was important to their QOL (see McDougall, Baldwin et al., 2015) and was only clarified by asking specifically about spirituality. In describing what was important to their QOL in the earlier paper (see McDougall, Baldwin et al., 2014), the youth used terms such as fulfillment, satisfaction, happiness, and enjoyment.

These youth initially spoke of their sense of purpose leading to satisfaction or fulfillment. However, it was not until the concept of spirituality was specifically explored with them that the youth began to reveal what this concept meant to them, and that it indeed was important to their life quality. This may be due to youth viewing spirituality as very personal or perhaps to youth not normally considering such an abstract concept. This suggests that it may be important to provide probes or to specifically ask youth about the importance of spirituality when studying the factors related to their QOL. Additionally, qualitative methods using narrative or creative expression may support youth in a deeper exploration of the relationships between their spirituality and their QOL than is possible in an interview format, especially with younger adolescents.

Summary

Our study findings indicate that many youth with disabilities have a personal definition of spirituality that may range from religious to scientific to philosophical in terms of how they create a sense of meaning and determine purpose in their life. Since youth with disabilities in this study have told us that their spirituality is important regardless of how it is defined, and that it is strongly linked with their QOL, it is expected that the findings from this research will be useful to pediatric rehabilitation practitioners in considering meaningful approaches to therapy for youth with disabilities. It is vital for clinicians to become more adept at exploring the unique meaning of spirituality for individual youth and its significance in their lives in order to support and enhance their QOL. As well, organizations providing youth services need to recognize the biopsychosocial and spiritual elements that may be important to consider in determining an array of services for youth with disabilities and their families. Further investigation into how spirituality may provide an underpinning for the generally optimistic ways that youth with disabilities can understand themselves and their disability, as well as their understanding of meaning and purpose as expressed through altruism, will be beneficial.

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